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Surgery or Surveillance How Do Women Decide when Tested Positive as a *BRCA* Mutation Carrier?

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Abstract

Raised awareness in the mutation genes known as, *BRCA1* and *BRCA2*, has dramatically increased the number of women undergoing genetic testing to inform them if they are at risk of developing breast cancer. This paper explores the main influences that can affect the woman's decision making processes when tested positive as *BRCA1* or *BRCA2* mutation carriers. The paper concludes that there is a need for a more informed and person-centred approach to genetic counselling for women post-test.

Introduction

By 1995 it became apparent that breast cancer susceptibility genes, *BRCA1* and *BRCA2*, were implicated in hereditary breast and ovarian cancers [1,2]. The presence of a *BRCA* mutation has been shown to significantly increase a woman's chances of getting breast or ovarian cancer in the future. The lifetime risk of breast cancer is as high as 70% for *BRCA1* mutation carriers, and 55% for *BRCA2* mutation carriers, while the ovarian cancer risk is as high as 40% for *BRCA1* mutation carriers, and 20% for *BRCA2* mutation carriers [3]. To put this into perspective, breast cancer is the most common cancer in females in the United Kingdom (UK), accounting for almost 31% of all female cases, while ovarian cancer is the sixth most common cancer in the UK, accounting for almost 4% of all female cases [4]. In what has been described in the media as the 'Angelina Jolie effect', there has been a marked increase in the number of women seeking referrals for genetic testing due to raised awareness of *BRCA* mutations [5].

A positive *BRCA* mutation carrier result can be psychologically overwhelming, and have a profound effect on the quality of life of the woman as they go through the decision-making process of managing their risk either by surveillance or surgery [6,7]. The delivery of genetic counselling is extremely important for women and their families at this time and this role is normally undertaken by advanced practice nurses pre and post-test. Genetic counsellors provide valuable support for those undergoing genetic testing for gene mutations, and help guide individuals through challenging and complex decision making to enable them to manage their risk based on clinical guidelines 164 [8].

The continued prevalence of breast and ovarian cancers coupled with increased awareness and demand for genetic testing and counselling, highlights the need for a strong evidence base for advanced nurse practitioners to ensure they continue to deliver current and effective care [4,5]. This paper discusses four key issues of proximity, social support, control and survivorship that surround the provision and delivery of genetic counselling post-test for women with a *BRCA* mutation.

Proximity

Women with a first degree relative that had been affected by breast or ovarian cancer tend to use a 'proximity filter' to assess their own perceived risk and determine the risk-management strategy of surgery or surveillance [9]. *"One way that I think my mom's death directly impacted me was that for a long time….I assumed I would get cancer and die early"* [10].

Jeffers et al. [11] suggested that those individuals with a *BRCA* mutation consider risk to be experiential rather than quantified. Furthermore, Litton et al. [12] reported that 84% of participants with a previous family history of breast or ovarian cancer felt that a risk reducing mastectomy was the most effective way of reducing their fear of getting cancer. This was evaluated to be a result of proximity to cancer which might begin years before they are tested for the *BRCA* mutation [9]. Hoskins et al. [10], claims that it becomes apparent that the loss of a mother or close relative connects the *BRCA* mutation carrierl with proximity to cancer. This is highlighted further by the reports that women who chose surveillance, did not have the same "lived" experience of a mother, sister or brother who died from cancer. As a result of no experiential proximity to cancer they continued with surveillance and 'perceived' cancer to be further away [9]. These differences in perception created by proximity require consideration during post-test counselling to ensure that a truly person centred delivery of care can be designed around the individual.

"I have…no idea what cancer looks like. I have no idea what cancer feels like….I've just got this big fat number the geneticist flopped in front of me when she gave me my status that says eighty-seven percent… .I have no sense how else to gauge it" [10].

Howard et al. [13] further contributes to this discussion through the self-schema theory which are mental representations of the self that can change over time based on a women's perception of risk. The self-schema theory is applicable to the proximity theme when considering how individuals perceive risk over time.

"I'm definitely getting a little bit stressed and tired of all the testing and wondering how much longer I want to do this…I'm considering doing it at a younger age and not necessarily having to breast-feed my children" [10].

Social Support

Social support and the need for follow-up sessions with genetic counselling is recognised as important so that women feel more supported.

"you give me this information and nobody has done anything about it…It's like somebody has given you a death sentence…I just don't think it's right to give people, tell people that and then there is nothing to back it up" [11].

From a different perspective it was found that partners of young *BRCA1* and *BRCA2* mutation carrier women are sometimes very involved in decision-making and planning for risk management. This type of social support seems to have a positive effect on younger women which is important as evidence suggests that they can feel like they are under a 'black cloud' [10].

"He came to the decision before I did…he sits me down and says, we need to have a talk. I think the plan needs to change" [10].

Unfortunately not all *BRCA* mutation carriers felt they were supported in their decision making which could lead to avoidance of contact with unsupportive individuals, thus creating an element of social isolation. *"But she [the family member] actually thought that risk reducing mastectomy was a stupid decision, and I had a few reactions like that"* [10].

Control

Control is pivotal to women during this genetic counselling time and whether the woman felt empowered or disempowered will have an effect on their post-operative recovery following any surgery. Supporting evidence from Hesse-Biber [9], identifies a distinction between "following and "choosing," and suggests that it parallels the concepts of disempowerment and empowerment. When viewed from this angle it becomes apparent that it is important for health care professionals such as nurses to treat the person and not just the cause to promote a person centred approach thus promoting empowerment and a sense of control with decision-making. *"I'm going to get cancer if I don't do something about it…I wanted to do something, to take control…I didn't want to be a cancer patient, I'm just going to have the surgery"* [9].

In terms of accountability, the use of evidence based practice is an essential element towards the UK National Health Service (NHS) operating in a cost-effective manner [14]. However, it is also important that professional standards and quality of care are not compromised as a result of the diminishing healthcare budget [15]. The clinical care guidelines (CG164) produced by the National Institute for Health and Care Excellence (NICE) [8], provide evidence based support for both practitioners and women affected by the *BRCA* mutation or those with a family history of breast cancer.

Although care delivery cannot always involve empowerment in a cancer diagnosis, it is achievable to promote a sense of control through empowerment via preventative treatment measures by adopting an integrated, informed and person-centred approach to genetic counselling [14]. The challenge faced with the effectiveness of genetic counselling is that the evidence is dominated by a medical healthcare model, were making sense of the *BRCA* mutation using statistics is the standard [9]. Contrary to this statistical approach this review has reported a 'nexus of decision-making' whereby women that are *BRCA* mutation carriers filter 'perceived' cancer risk according to experience and proximity to cancer rather than statistics. This more experiential approach taken by women therefore questions the current style of genetic counselling were statistics and probability equations could be potentially ineffective to assist decision-making for women with the *BRCA mutation*.

It could be suggested that this is further corroborated by supporting evidence that a significant number of women are seeking social support online due to perceived deficiencies in genetic counselling [13]. Although it could be assumed that in todays 'e' modality women will naturally review the available material on the internet to help in the decision making process. Indeed a study by Wang et al. [16] indicated that breast cancer is one of the most popular medical search queries on the internet in America. *"I did go on the internet and read, get some literature and books, talk to the doctors…I think I made the right decision and I think I based that decision on what I think I know."* [13]. It is extremely important that genetic counsellors are aware of the websites most frequented by women, so that they have the evidence to guide and support women through the many hurdles and sometimes conflicting evidence available online.

Haffty and Lannin [17] promote risk reducing mastectomy in women with a family history. However, the evidence recommends a cautious and neutral approach to guidance where the woman has less social support in her personal life and is relying on health care professionals to empower her by guiding her through the decision-making process based on the CG164 recommendations [8]. This is crucial to avoid women having feelings of regret and disempowerment on their decision-making post-surgery. *"You have to have a mastectomy…I had no information. I went in blind, and I had no one to talk to…I had my doctors and their nurses, and everybody was great, but that's all…. (if I choose surveillance)…I guess I die…And that one sentence did it for me"* [9].

Survivorship

This final issue considers the element of survivorship throughout the decision making process. Howard et al. [13], claimed that the self-schemas theory promotes survivorship in four contexts including protecting one-self from cancer, identity, emotional well-being and relationships. On balance, women weigh the potential benefits and consequences of management options to 'protect themselves from cancer'. *"I definitely weigh pros and cons…….the risks of the surgery were minor compared to the risks involved with cancer"* [13]. In terms of identity and emotional well-being, women consider the impact of choosing invasive surgery to manage their risk. When considering relationships affecting decision-making, women consider how survivorship is important to their role and responsibilities as mothers, wives, partners, sisters, and daughters [18]. The paramountcy principle was an overriding factor for choosing the surgical route in the literature as women balanced their individual needs against the needs of present or future children and their role as a wife and mother.

"I'll be driving on the road…and I literally have daydreams that I have two kids. I'm gone. I have two kids and… I'm not there…I want to make sure I'm around…Whatever that takes" [10].

Conclusion

This paper has explored the effectiveness of genetic counselling in women who are *BRCA* mutation carriers. There is a sense that the current medical model in use is dominated by statistics and needs adapted to take into consideration qualitative evidence that explores the woman's quality of life post genetic testing. Although statistics are an important element of informed risk assessment, the qualitative evidence would suggest that women who are *BRCA* mutation carriers may base some of their risk-assessment on a 'nexus of decision-making,' and thus filter perception of risk via experiential rather than quantified outcomes [11]. By providing a more balanced view in terms of statistical probabilities and quality of life, the woman's decision making process should be a more improved and informed approach.

The key issues discussed in this paper that of proximity, control, social support and survivorship need to be explored through genetic counselling with a patient-centred approach as well as a familial approach to improve quality of life. Proximity to cancer and experience of a close relative with cancer were vital aspects that influenced decision-making across the spectrum. Women were more empowered by their decision-making when they were in control compared to those who attributed disempowerment to a lack of control. Furthermore, Social support became more prevalent when there was no familial experiential proximity to cancer. Survivorship identified on-going long-term support needs such as body image, identity, emotional well-being and effect on relationships. Survivorship issues span long beyond the scope of this discussion but include support needs related to having children in the future either via IVF or other means, coping with a new body image and the effect that has on their relationships whether married or single.

These four key issues of proximity, social support, control and survivorship should be considered as an integral part of all genetic counselling in order to minimise the psychosocial impact and improve the quality of life for women who are *BRCA* mutation carriers. Neutral genetic counselling without prejudice is crucial for a woman to take ownership of her risk promoting empowerment as opposed to the 'one-size-fits-all' approach that tends to be based on statistical significance rather than patient centred outcomes.

Further qualitative exploration in this area is necessary in order to inform clinical practice and provide women who are *BRCA* mutation carriers with the person centred care they require post genetic testing. The key issues discussed in this paper could be used as a means to shape future research and systematic review into this expanding area of health care.

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